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Public Expectations of Gene Therapy: Scientific Futures and their Performative Effects on Scientific Citizenship

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Keywords: Scientific citizenship, Sociology of expectations, PUS, Gene therapy, Mass Media.

Abstract:

The paper combines a criticism of Public Understanding of Science (PUS) with the 'Sociology of Expectations' in order to examine how particular expectations towards scientific progress have performative effects for the construction of publics as citizens of science. By analysing a particular controversy about gene therapy in Denmark, the paper demonstrates how different sets of expectations can be used to discriminate between three different assemblages: the assemblage of consumption, the assemblage of comportment and the assemblage of heroic action. Each of these assemblages make medical science, scientific citizenship, politics, patients, doctors and expectations towards the future emerge in particular ways. By their radically different expectations towards science and their different constructions of what it means to be a scientific citizen, the assemblages construct the objectives of the governance of science in three very different ways.

Claims about scientific progress and future technological possibilities are often described as rhetorical devices, employed to hype a particular field of research in order to attract attention and resources (Levidow & Marris 2001; Holtzman & Marteau 2000; Nelkin 1995). It has, however, also been argued that we should study the ‘sociology of expectations’ (Hedgecoe & Martin 2003; Brown, Rappert & Webster 2000) in a less normative fashion, trying to understand the performativity of these expectations in shaping the ‘present’ (Michael 2000, 34). Expectations towards the future should be understood as a major resource which actors draw upon when they seek to enrol other actors in networks of technological innovation. In that sense they function as productive representations, which shape the conditions of possibility for the development of science and technology. The present paper makes an attempt to follow this argument about performativity by focusing on the simultaneous co-construction of *scientific citizenship* and *expectations towards the future* in the media coverage of a particular experiment with gene therapy involving liver cancer patients in Denmark.

The notion of scientific citizenship (Irwin 2001) points to an increasing awareness of the intermingling between science and society. It implies that scientific knowledge is important for citizenship in contemporary society, but also that citizens can lay a legitimate claim about accountability on scientific research. As such, the notion can be perceived as a normative ideal concerning the appropriate form of democratic governance in a society which has become increasingly dependent on scientific knowledge. The present paper, however, is not an exploration of this ideal in order to define normative directions for governance of science. Rather, it is an effort to explore the constructions of ‘scientific citizens’ in specific debates about scientific futures in a particular local context - in this case the Danish discussion about gene therapy as a possible cure for cancer. It does so by asking how particular visions of gene

therapeutic futures and of scientific progress have performative effects for the construction of *publics* as citizens of science, that is, citizens who have *some form of legitimate role in the governance of science*. In this way the paper contributes to developments in the tradition of Public Understanding of Science (PUS), which stress the need to analyse how '*publics*' are contextually composed as a complex and heterogeneous set of actors and relations (Irwin & Michael 2003; Locke 2002; Michael 2002).

In relation to public understanding of science, Denmark has been characterised by high levels of general education, cultural homogeneity and a consensus-seeking political culture (Jelsøe et al. 1998). In efforts to resolve controversies about science and technology – and biotechnology in particular - methods of facilitating public deliberation have been implemented in various ways over the last 20 years, with the consensus conference as the best known example (Andersen & Jaeger 1999). Despite the many participatory efforts, however, biotechnology has remained high on the Danish public agenda as a controversial issue. Judging from Danish media coverage, human cloning is seen as very problematic whereas topics such as genetic testing, pharmacogenetics and gene therapy have been discussed as mixed blessings, with a focus on potential benefits as well as risks.¹ In general, much of the hope vested in these technologies has been founded on general expectations towards future therapies rather than concrete scientific results. This is particularly true for the issue of gene therapy, which has been surrounded by what Stockdale in a US context has called 'an aura of miracle technology' (Stockdale 1999). Similarly, Danish media reports in the latter part of the 1990s have most often left the impression that major breakthroughs in gene therapy were waiting just round the corner, without, however, presenting tangible results to sustain these expectations (Horst 2003).

One incident, nevertheless, has not followed this general pattern of media coverage of gene therapy. This was an experiment with gene therapy on liver cancer patients at a regional hospital in Denmark in 1999. The experiment was prematurely suspended due to ‘irregularities’, and this suspension and its aftermath created a lot of attention in the Danish mass media. At the centre of this attention were basic questions about expectations towards the future and the possibility that scientific research would eventually produce a cure for cancer. The argument of the present paper is that these expectations towards gene therapeutic futures were simultaneously co-constructed with notions of rights and responsibilities of the various actors involved, be it scientists, doctors, patients, politicians or broader publics. The paper, therefore, investigates the mediated articulation of this experiment and its suspension, in order to explore the simultaneous construction of medical science, its publics (as patients and citizens), and expectations of a cure for cancer.

Conceptual framework

Within the academic tradition of public understanding of science (PUS) it is common to distinguish between a traditional and a critical version, where the second is based on a criticism of the deficit model employed by traditional PUS (Durant 1999; Wynne 1995). According to this criticism, traditional PUS has tended to perceive of *the* public as a national unity of lay-people characterised by greater or lesser degrees of scientific literacy. In contrast to this perception, critical PUS has argued that the public should be seen as composed of locally situated groups, each of which makes sense of scientific knowledge in their own way. When viewed in their local contexts, particular instances of sense making, previously characterised as ‘defi-

cient', now seem perfectly reasonable (Irwin & Wynne 1996). Critical PUS has, however, been open to criticism also, as it has been argued that this tradition paints a similarly simplistic picture of the communicative relation between science and society (Irwin 2001; Miller 2001; Michael 2001, 1998; Locke 1999). As one example, Michael points to a tendency to romanticize the public within critical PUS. Groups of lay people are often depicted as homogeneous entities without any analytical sensitivity towards internal differences and cultural dynamics stemming from relations with other cultural domains in society. As opposed to the idealised consensual deliberation in public imagined by critical PUS, Michael argues that we should realise that the consumption of science is distributed and fragmented, and that mechanisms of evaluation are closely connected to contextual utility, which might differ between individuals (Michael 2001).

Building on such criticism, Irwin and Michael have suggested that we substitute the contrast between expert and lay (or between science and society) with the notion of conflicting *ethno-epistemic assemblages*. As coalitions or hybrid groups these assemblages are characterised by heterogeneity and fluidity. They are composed of scientific as well as other forms of knowledge and resources. The concept of assemblage does not imply a fixed and unchanging entity, but rather transitory communities 'that coalesce and then melt' (Irwin & Michael 2003, 108).

The fluidity of the assemblages implies that they are under continuous construction and deconstruction. An assemblage is not a once-and-for-all composition of pre-existing constituents, but rather co-constructed with the actants that are seen to be part of it, including the particular enunciations of science, society and nature. In this context, the important point 'is that such enunciations *have effects*' (Irwin & Michael 2003, 129). It is out of assemblages and the

complex relations between various assemblages that publics and ‘scientific citizens’ of various sorts emerge. Drawing upon the literature on ‘governmentality’ (Foucault 2000; Dean 1999; Rose 1999), Irwin & Michael argue that to study governance in relation to publics and the ‘scientific citizen’ is ‘to ask a number of questions about how such a citizen has been formulated. Indeed, it is to ask what such a scientific citizenly self *is* such that it *can* be governed’ (Irwin & Michael 2003, 130). Publics (or scientific citizens) have no independent existence, but are relationally co-constructed together with ‘science’, ‘experts’, ‘patients’ and all the other associated entities that are necessary for a particular assemblage to take form, and a particular form of governance to be considered legitimate.

The concept of ethno-epistemic assemblage has some fruitful analytical implications for the study of publics due to the emphasis on heterogeneity and fluidity. These analytical benefits, however, also pose some challenges if the concept is to be employed in empirical analysis and not merely as a heuristic term. The difficulties arise because the emphasis on heterogeneity and fluidity makes it difficult to identify and delineate actualised assemblages as objects of study. On a theoretical level this indeterminacy is exactly the point in arguing for the rhizomic character of the ethno-epistemic assemblage. But the implication is that there is no general guideline that makes the analyst able to determine what does and does not belong to the assemblage. Put bluntly, this is a problem of analysing *stability in fluidity*, which generally can be considered a common problem for many post-structuralist analyses within STS. Rather than embarking on a theoretical discussion of ‘roots’ and foundations, however, the present paper has sought to deal with the problem in the actual analysis. Although assemblages can’t be *universally* defined and delineated, it is possible to do so in *particular* contexts by using a well-defined analytical discriminator for the identification of specific assemblages. In the pre-

sent paper, expectations towards the future are used in this way. The central idea is that enunciations of a specific kind of expectation of a gene therapeutic future can be used to identify a specific ethno-epistemic assemblage.

According to Michael expectations can be analysed as *representations of the future*. They constitute a way of ‘managing’ the present by articulating a particular future as ‘the *place* where solutions are realised, presences manifested, and wrongs righted’ (Michael 2000, 22). This outline is fruitful in the context of this paper, where the analysis focuses on assemblages as they emerge in the mass mediated articulation of a controversial issue. Building upon the longstanding STS rationale for controversy studies, ie that public controversies make explicit what is otherwise left unstated (Nelkin 1979), this paper argues that public controversy reveals the existence of competing representations of futures. Controversies, in this context, are defined as disagreements about current problems and their future solutions. Furthermore, the competing representations of the future simultaneously point to assemblages of hybrid identities in the present. Any representation of a future solution (for instance of gene therapy as a working future therapy) is closely linked to a particular construction of a problem of the present (for instance the problem of cancer) and a number of associated entities. Medical science, patients, relatives, politics, rules of experiments, all emerge as particular elements in the heterogeneous grouping of the assemblage in order for a problem to be constructed in a specific way.²

On this basis, the paper presents an analysis of ethno-epistemic assemblages as the *enunciation* of sets of co-constructed problems, solutions and identities. The analysis is inductive and entails two interrelated steps:

- The first step is to identify different sets of expectations by analysing the articulation of current problems and future solutions. It proceeds from the following research questions: How is the specific experiment with gene therapy articulated as problematic? What are proposed as solutions to this particular problem? How are these enunciations of problems and solutions linked to representations of medical futures in general?
- The second step is to look at these representations of the future in terms of their '*performativity*' in relation to the construction of the public and the scientific citizen. This part of the analysis proceeds from the following research questions: How does the specific content of a future construct particular identities as publics, scientists, patients, politicians? What are the relations between these identities? What is the particular ethos associated with each of these identities in order for a particular vision of the future to be fulfilled?

The empirical material for this analysis of representation derives from Danish newspapers. As a major arena for public debate about biotechnology, the mass media are a fruitful source of empirical data (Bauer 2002; Gutteling et al. 2002; Priest 2001; Nelkin & Lindee 1995). In this context, however, it is important that mass mediated articulations are not simple transmissions of events taking place outside the media. First of all, news is constructed according to a number of specific norms and practices as discussed in media sociology (Berkowitz 1997). Secondly, and more important in this context, mass media should not be understood as an arena for representations of other - more genuine or important - practices taking place elsewhere. Mediated accounts of phenomena are enunciations which have effect by translating individual experiences into *public* experiences, thereby constructing these experiences as relevant public

issues. The enunciations are part of the public knowledge on gene therapy and medical science, and as such they have constitutive influences for how the public ‘do politics’ in relation to science, that is how they are scientific citizens (Irwin & Michael 2003, 122).

The function of the media in ‘doing politics’ has been analysed as a question of agenda-setting (see fx McCombs 2004) or news media as a political institution (Cook 1998). In the present context, however, the focus is on the way expectations and identities are co-constructed in the mass media, since this is seen as an important part of the construction of the scientific citizen and the governance of science. Whereas ethno-epistemic assemblages clearly consist of more than what is said in the media, these articulations ‘do politics’ by shaping identities of ‘publics’ and accounts of public knowledge. This is not an argument in favour of a classical ideal of public opinion formation as the basis for parliamentary democracy (Habermas, 1991). In accordance with the concept of assemblage, the argument is simply that the construction of publics and public opinions (whether in opinion polls, mass media or policy reports) is co-constructed with the possibilities for governance of science in society.

Within this methodological framework, the paper presents an analysis of the way in which the suspended experiment with gene therapy was articulated in three Danish national newspapers. Together these three papers embody a relatively broad spectrum of editorial styles. They include the two largest broadsheets, one social-liberal (*Politiken*) and one conservative-liberalist (*Jyllandsposten*) as well as the biggest tabloid (*Ekstra Bladet*) which has a reputation for being the most populist tabloid in Denmark.³ The analysis includes all articles about the suspended experiment (both news and views) in these three papers, altogether 92 articles.⁴ The coverage, however, is unevenly distributed across the three papers. *Jyllandsposten* covered

the case very intensely (38 stories in the following two months and subsequently 26 articles in the next half year). In this context it should be noted that *Jyllandsposten* had a local interest in the story, since the paper is based in the city of Aarhus where the suspended experiment took place (it is the only national daily newspaper not based in the Danish capital). *Politiken* covered the story less intensively (17 stories in the two following months and only 3 in the subsequent half year) and used a high degree of wire service news. *Ekstra Bladet* covered the story with 3 articles in the first two months and 5 articles in the following half year. These differences, however, are not crucial to the present analysis as it is not a primary ambition to look for differences between the three papers. Rather, the totality of articles is analysed with a view to identifying different enunciations of expectations and scientific citizens according to the above mentioned research questions in the two interrelated analytical steps.

In accordance with the Foucauldian tradition of discourse analysis, the analytical unit is not the newspaper article, but rather the enunciation (understood as an articulation productive in a particular way – in this case the enunciation of problems and solutions) (Foucault 1992; 79-87). The implication is that some newspaper articles include more than one type of enunciation, whereas others include none. The analysis is therefore initiated by identifying the totality of enunciations and subsequently searching for patterns of similarities and differences between them. With one important exception, which will be discussed in the conclusion, these patterns spread across the three newspapers. In the following analysis the patterns are presented using a few selected quotations as illustrative examples. The quotations have been translated as loyally to the original text as possible, even if this has meant reproducing an unclear sentence. On the basis of the present analysis it is not possible to make claims about the

strength or prevalence of the patterns of articulation. Rather, the objective is to present a qualitative analysis of the enunciations of scientific futures and their performative effects.

Introduction to the case

On July 1, 1999 two large national broadsheets in Denmark featured a story about the extraordinary decision to suspend a clinical experiment⁵ with gene therapy at a hospital in Aarhus (the second largest city in Denmark). Early coverage focused on the decision to suspend the experiment. Apparently, safety procedures had been contravened, the clinical protocol for the experiment had not been followed, and patients had been sent to London for treatment in return for large financial donations. According to the media this had led to the suspension of the experiment and the resignation of Steen Lindkaer Jensen, the doctor in charge. In the following weeks the mediated coverage concentrated on a group of patients, barred from gene therapy because of the suspension. Since these patients had apparently been promised gene therapy, an extra-ordinary emergency plan for their treatment was organised. Later coverage focused on investigations of the accusations against Lindkaer Jensen carried out by various parties. The criticism culminated when a report from a team of five university professors was made public in the beginning of September. This report criticized the management of the experiment, but since Lindkaer Jensen had already resigned no further action was deemed necessary.

During the coverage the specific story of a doctor's mismanagement of his relationship to patients was translated into an exemplary story about the governance of medical science in general. In this context, some articulations focused on the rights of patients and others on the responsibilities of doctors and this led to the enunciation of two distinctively different expect-

tations for the future as well as two distinctively different ways of constructing the scientific citizen. The focus on *patients' rights* enunciates a scientific future in which medical science is expected automatically to deliver future working therapies, which can then be consumed by the scientific citizens. In contrast, the focus on *doctors' responsibilities* enunciates a possible future therapy as dependent on a particular kind of 'proper' behaviour on behalf of all the involved actors, including patients. In addition to these two, however, the media articles enunciate a third type of expectations towards the future, which is based on *heroes of action* rather than science and scientific citizenship. In the following, each of these sets of articulated expectations will be explored separately in order to demonstrate how they are co-constructed with various identities thereby pointing to three different assemblages. In the concluding section I will address the performative effects of these assemblages on the way in which science and scientific citizens can be governed.

Patients' rights

During the first weeks the media interest was concentrated on a small group of 8-10 patients, who apparently had been promised gene therapy by Lindkaer Jensen, but had not received it by the time of the suspension. In this situation the authorities are described as saviours when they establish an emergency plan to fulfil this promise, although the principles behind the plan are controversial. It is presented as extraordinary to offer this treatment outside the scope of a research experiment, but the emergency plan is commonly articulated as a justified solution:

The chairman of the central scientific ethical committee, Kamma Bertelsen, is in principle against permitting gene therapy as treatment, when there is no

documentation of effects and side effects: 'The fact is that nobody knows anything about the treatment. But because an unfortunate situation has arisen, where ten patients have been promised hope, I find it justified that they receive treatment as long as the authorities will vouch for it' she says.⁶

The epithet 'emergency' as applied to the plan is justified by articulating the patients as victims, with a rightful claim to gene therapy. The patient is enunciated as a user with certain legitimate rights and the health care system is contractually obliged to fulfil certain obligations towards the patient. The crucial issue is the right of patients to receive a treatment when promised one, and it seems that the expectations of positive effects in themselves legitimate the offer of treatment. The articulated problem is not whether the therapy will work as treatment, but whether the patients will receive it or not. It is noteworthy that none of the articulations of this emergency plan seriously argue that it will have a curative effect, but it is implied that there will be some sort of positive effect. In general, it seems to be an undisputed expectation that medical science will deliver results if it pursues the possibilities posed by gene therapy:

The CD [Centrum Democrats] party now advises the government to establish a special council, which is to survey all future experiments with gene therapy in humans. (...) 'I am convinced that gene therapy will substitute traditional medicine in the future and that is why we have a special obligation to keep an extra eye on this research'.⁷

Often the lack of documented effect is made up for by expectations towards the future:

*“Those gene therapies have to be continued, not opposed. They are the future.”*⁸ It might be that the therapy has not yet proved effective but this problem is articulated as merely a question of time. The argument seems to be that, if allowed to follow its own logic of inquiry, medical science will undoubtedly lead to a breakthrough in gene therapy. With regard to the rights of patients, however, this poses a central problem. Precisely because medical science is following an internal logic, it is not able to take externalities, like the rights of patients, into simultaneous consideration. As an external mediating source of power, politicians therefore need to regulate the interaction between doctors and patients:

If we are to maintain the people’s trust in scientific experiments we have to give the research ethical committees a practical way of following up on the licences they issue to the researchers. It would also be appreciated if it were complemented with random controls. As long as researchers know it can happen they will have a preventive effect.⁹

In arguments like this, control of research in the health care sector is enunciated as a kind of consumer protection. In order for the patient to be treated fairly and decently it is necessary for an external agent, in this case the government, to control the actions of researchers. The external regulation, however, is also understood as being in the long-term interest of science itself, since it will secure patients’ trust in medical research. If people do not trust scientific research, they might not partake in scientific experiments and this could be devastating to the future development of new gene therapies.

The crucial point in this connection is that contrary to what is claimed in opposing arguments, regulation is not imposed in order to impede scientific research. In principle it is not questioned that science will create important results if left to pursue its own objectives. But external regulation is needed to ensure that the powerful scientific quest for solutions to the problem of cancer will not have unintended side effects in the form of a misuse of patients. In this way the argument bears some resemblance to the advocacy for the regulation of market forces undertaken in most welfare states. Here, however, it is not the negative consequences of economic market forces but of the logic of scientific inquiry, which has to be controlled by the central authority of the state. Scientific progress has its costs, and the role of politics and other external forces is to prevent these costs becoming unacceptable, and/or to prevent them destroying the basic foundations of science itself.

Regarding the construction of scientific citizens, these enunciations primarily construct the patients as consumers of science, or to be more precise, consumers of the products of research: that is, treatments. The relation between medical research and its publics is therefore one of demand and supply, although it should be noted that there seems to be a kind of ethical obligation to meet demand with supply. Patients have a right to consume research-based health care treatments, and insofar as all members of the Danish public are potential patients, they are also potential consumers of science.

In general, however, the public or publics, as composed of larger groups of Danish citizens, do not seem to have an active role in the regulation of science. There is no direct articulation of the general public as a political power, but it seems to be on its behalf that the politicians claim to be acting when they assume the responsibility for deciding about the external regula-

tion of science. In this way, the scientific citizens have ‘delegated’ their political powers to the politicians, who are central actors in this assemblage. Thereby the enunciations demonstrate that the exercise of consumer rights is crucially dependent on a central mediating force, which functions as a guarantee for these rights. The market for consumption of science does not exist by itself, but has to be actively created and maintained by state authority.

Doctors’ responsibilities

A different set of enunciations focuses on the responsibilities of the doctor executing the experiments rather than the rights of patients. One recurrent issue is the careless clinical conduct of Lindkaer Jensen. Another issue is the apparent financial demands made on the patients. In Denmark the health care service is free of charge: introducing the question of paying for a treatment is articulated as morally reprehensible, particularly since there was no scientific guarantee that the treatment would have any effect:

Chairman of Danish Cancer Society, Jens Kristian Goetrik, criticises the liver doctors for having suggested great prospects to the patients: ‘It is quite unfair to suggest great prospects to very ill people, when you don’t have any documentation that it is true and on top of that to demand money for it.’ (...) ‘The doctors have no guarantee or documentation that the treatment will help. Still you suggest great prospects. Anyone would sell all their belongings and this is why it is close to deception’, says Yvonne Herloev.¹⁰

This quotation enunciates patients as people who will be prepared to do anything in order to be cured of cancer. In this vulnerable situation it is especially important that doctors do not take advantage of the situation and exploit their position of authority to further selfish interests. Instead, doctors should assume responsibility for the patients, both in specific experiments and in medical research in general:

As a responsible doctor you withhold comments on research until it is concluded and you know the facts. Otherwise you risk making a lot of unhappy people insecure and confused and creating false expectations. Mortally ill patients' time is precious.¹¹

By articulating the time remaining to dying patients as too precious to squander on false expectations, a particular moral is installed, where the important thing is to face one's fate. Dying patients should acknowledge that their time is running out instead of clinging to a false hope of being cured. In this situation, doctors are constructed as subjects who should assume the responsibility for guiding patients in the proper direction:

“As a doctor it can be very difficult to say no. The temptation to venture outside the protocol is extremely high,” says Jens Astrup. “But from the point of view of medical research one must insist that experimental treatments have to follow the protocol strictly. Otherwise we will treat a lot of patients without knowing for certain whether the treatment has worked. In the worst case we would be tempted to use a lot of resources on a

promising treatment, which is later demonstrated to have no effect, and then we have given patients a false hope,” says the professor.¹²

As exemplified in this quotation the expectation that medical science will find a cure for cancer in the future is made dependent on a specific behaviour by doctors and patients. In contrast to the previous set of articulations, where it was almost taken for granted that scientific research would deliver working therapies, these enunciations construct the future cure as less automatic and place great emphasis on the necessity of hard work: “*Realistically, one should not expect an immediate miracle cure. Rather it is a slow and laborious job which only gradually will begin to bear fruit.*”¹³ The notion of a miracle is used several times as an articulation of what medical science is *not* about and what researchers do not do: they are not miracle workers. Although these enunciations all seem to subscribe to a general sense of hope and progress brought about by medical science, the development of effective therapies is dependant on hard work and the right attitude.

The problem with Steen Lindkaer Jensen is that he has conducted impure scientific research by disrespecting the methodological considerations, taking advantage of the patients’ desperate hopes for cures and introducing financial claims. Thereby he has contaminated medical research and this contamination has to be countered by sound scientific knowledge and practice. Opposed to his improper conduct, other researchers within the scientific system are constructed as responsible with regard to their duties and obligations: “*We are in an initial phase with gene therapy, where we have to ensure that all results are documented in the right way.*”¹⁴

Researchers, however, are not the only actors who have to behave themselves according to a particular pre-defined role. Rather, all involved parties need to pay due respect to the logic of scientific inquiry. Just as researchers should acknowledge their responsibility to protect patients from false expectations, patients should cooperate as ‘comported’ patients (ie. with ‘personal bearing’, www.com.oed), who accept their destiny and realise that they are mortally ill. They should not have high hopes, or wait for miracles, but realise that the eventual cure for cancer by gene therapy will be dependent on hard work and their comportment according to the designated roles. In this way a distinction between expectations is introduced. On the one hand, there are the ill-founded expectations of miracles based on false hopes and fairy tales, on the other hand, there are the ‘sound’ expectations based on scientific methods and proven facts.

In this context external regulation is articulated as unnecessary or even damaging to the scientific production of knowledge. Precisely because it is external, it will not respect the internal norms and standards of science. Thereby it runs the risk of ‘contaminating’ science and consequently it might do more harm than good. Politicians, therefore, should not engage with science in order to enforce any form of regulation. Rather, they should leave it to the scientific system and its internal hierarchy to make researchers behave in the proper fashion: “*We are in favour of de-centralised self-justice*”¹⁵

In this way, science is enunciated as a particular system of knowledge production incorporating only formally engaged actors: researchers as subjects and patients as objects. External actors, such as politicians, relatives and other lay people should not interfere with science because the contamination might jeopardize the quest for true knowledge. To be a scientific

citizen within this assemblage is to be able to comprehend and receive the scientific results and assist as comported passive objects of research. It is not to be actively engaged with science by exercising consumer rights or proposing external regulation. In line with the traditional model of PUS, the scientific citizen educates herself so as to understand the scientific knowledge about diseases and cures and obey the scientific logic of inquiry rather than believing in miracles.

The hero of action

In stark contrast to the two sets of enunciations focused on either the rights of patients or the responsibilities of doctors, there is a third set which articulates the hopes of curing cancer completely differently. In these enunciations, the expectations towards a future cure are not connected to medical science in general. Rather they seem to be individual resources for the specific patients struggling against cancer. Consequently, the articulation of Lindkaer Jensen is exactly the opposite from the previous enunciations. Rather than creating false expectations his efforts are described as a ‘last chance’ for patients that nobody else cares about. Instead of being a criminal outsider or an irresponsible practitioner of medicine, he is a hero and a genius:

Professor Lindkaer is really a friend of the patients. It may be that he has left some things in a mess and that safety procedures have not been followed and that the manipulated virus was contaminated. But what does it matter, when it helps,’ says the son. ‘My father has gained 10 kg after the gene treatments. Now he can fix both the house and the garden and he couldn’t

do that three months ago,' says the son and compares Lindkaer to Einstein, who also needed help with practicalities from those around him. 'Who wouldn't take a risk, if you had been told you were going to die' says the son.¹⁶

Two things are worth noticing in this quotation. First of all the treatment is articulated as a working therapy, or at least it is not seen as problematic. Secondly, however, this is not a decisive fact. It does not matter fundamentally whether the chances are large or small when justifying the experiment. Even the slightest chance is reason enough to justify the experiment, and Steen Lindkaer Jensen is praised for offering this last chance. He is a hero fighting to save the lives of mortally ill patients. This articulation, however, leads to the enunciation of the health care system as the main problem:

I feel fine and the British-Egyptian professor, Nagy Habib has told me that I do not have cancer in the liver any more. The ten tumours have disappeared after my gene treatment and I feel privileged that I had the 210.000 kroner that my treatment has cost me. But I think it is scandalous that Aarhus Municipal Hospital is so oriented towards economy that I survive because I have the money, while the person in the next bed dies.¹⁷

It is interesting to note how the saving of this patient is articulated as almost dependent on luck. He was privileged to have the money, while the imagined patient in the next bed was not so fortunate. The hospital, on the other hand, is constructed as a system that ignores the interests of the patients and acts instead on financial grounds. Thus, in order to defeat cancer, it is

also necessary for the patients to fight ‘the system’, because the establishment and its book-keepers have abandoned the chance of curing cancer on the grounds of what is seen as irrelevant:

The case tells us something about book-keepers and a machinery of power, which runs whatever way the wind is blowing. The victims are the mortally ill cancer patients, which on top of their harsh destiny have experienced that the treatment was suspended, resumed and stopped again while the parties involved in the smear campaign against Lindkaer ran to and fro with vague rumours and hear-say. Formalities and loose allegations were more important than the cries for help of mortally ill patients, and the continuation of a treatment that has given them one last hope. Now the politicians and the hospital promise to turn over a new leaf. The treatment will be resumed immediately. But without Steen Lindkaer. He was cut out by the book-keepers. The way the system works, they win almost every time.¹⁸

These articulations do not stress the need for rigorous scientific methods as the road to scientific progress, but focus on the treatment of specific individual patients. Crucial in this context is a belief in action and chance rather than rule-following behaviour: “*I am an unstructured person, but I don’t think book-keepers make good researchers or doctors*”¹⁹. Lindkaer Jensen is a hero, not because he is a scientist systematically producing reliable knowledge, but because he is taking chances in the struggle against cancer instead of just adhering to statistically established predictions of incurability. Consequently, what were presented as ‘scientific’ accounts of the lack of effect of Lindkaer Jensen’s experiment in the previous assemblages is

here understood as “*a struggle for power which was all about stabbing the leader of the ground breaking research project, cancer professor Steen Lindkaer Jensen, in the back*”²⁰

Caught in the middle of this power struggle, patients are described as legitimately trying to win the fight against cancer by believing in ‘the last hope’. This hope is not connected to a particular phase in the disease or a tangible experience of being cured by Lindkaer. Rather, it is based on a particular ethos, where ‘lucky’ solutions to problems might appear if, and only if, the individual is acting to pursue even the vaguest chance. The individual is basically alone, not able to depend on systems or general norms or regulation, but left to fend for herself in a hostile world. As an institution, medical science is not constructed as a beneficial social activity and a source of future cures of cancer. Rather, the individual hope of surviving a deadly disease is dependent on the pursuit of individual chances created by heroic action. It is not by acting as a consumer or an object of science that cancer will be defeated, but only through individual bets on chance and hopes of meeting an action hero.

Constructing futures and citizens

The basic argument of the paper is that enunciations of a specific kind of expectations of a gene therapeutic future can be used to identify a specific ethno-epistemic assemblage. Following this analytical strategy, three different assemblages have been identified in which medical science, patients, expectations, governance of science and publics emerge differently. The articulations focused on the rights of patients construct an *assemblage of consumption* where medical scientists are producing goods in the form of knowledge and cures. In so far as this production involves patients, their consumer rights have to be protected by rules set out by the state. The articulations focused on the responsibilities of doctors evoke an *assemblage of*

comportment in which the relation between scientists and other actors is a one-way dissemination of knowledge. True knowledge, however, can only be successfully produced if all involved actors behave according to their prescribed roles and obligations. And finally, the articulations focused on the last hope construct an *assemblage of heroic action* in which the individual patients can only hope to encounter an action hero, who might provide them with a last chance, since medical science is not expected to produce anything of value to specific people in need of a cure for cancer.

The *role of expectations* is very different in each of the three assemblages. In the assemblage of consumption, expectations towards future cures for cancer seem to be unproblematic. They are performative in so far as they are a major factor in the distribution of resources to science, but they are not an object of questioning in themselves. In the assemblage of comportment, however, the character of these expectations is a crucial factor in the representation of gene therapeutic futures. If the expectations are false or based on hopes for miracles they might jeopardise the scientific quest for a cure of cancer. So the possible future solutions depend on the present management of expectations. The implied relation between present expectations and future solutions is also important in the third assemblage of heroic action. But the framing is exactly the opposite, since the ‘false expectations’ are here depicted as ‘the last hope’, and it is only by pursuing this hope that patients might be lucky and get cured of cancer.

Scientific citizenship has been defined as the construction of *publics* as citizens which have a legitimate role in the governance of science. In the context of the particular gene therapeutic experiment it seems that the subject category of *patients* has been granted a lot of attention compared to, for example, the more general ‘public’.²¹ There are, however, striking differ-

ences with respect to the construction of agency in the different assemblages. In the first assemblage, the patient is an, albeit vulnerable, subject that consumes the commodities produced by science. The scientific citizen is primarily a well-protected customer. In contrast the second assemblage constructs the patient as a passive subject, whose only obligation is to comport herself as a responsible object of research (and disease). To be a scientific citizen in this context is therefore to let oneself be informed by science and to accept that a possible cure for cancer is dependent on the uncontaminated scientific production of knowledge. With regards to agency, therefore, politicians are a central mediating actor in the first assemblage, whereas the scientists are the vital agents in the second assemblage.

The most active patient, however, is found in the third assemblage of heroic action, where the patient has to fight both the disease and the health care system. It should be noted, however, that this active patient is simultaneously very dependent on luck. Action is considered positive, but the successful outcome is still dependent on chance. Hence this assemblage is to a certain degree characterised by fatalism. On the other hand, patients can only be lucky if they act. The disregard of science as a social institution in this assemblage is based on a profound lack of acceptance of science as a beneficial or truth-producing facet of society. The heroic element of this assemblage is therefore not related to a scientific quest for knowledge, but to the will to experiment with treatment on specific patients in need of cures. Speaking of scientific citizens in the assemblage of heroic action we therefore have to stretch the definition of citizenship, since the individual patients do not have a relationship to science as a social institution, but rather to individual heroic scientists.

In this context it should be noted that the three assemblages do not emerge in the same way in all three analysed newspapers. Whereas the two broadsheets enunciate all three assemblages, the tabloid *Ekstra Bladet* primarily enunciates the assemblage of heroic action. However, following the concept of ethno-epistemic assemblages it would be wrong to simply say that the three assemblages are interpretative frames, which the media employ according to their editorial profile. Rather, the media's editorial profiles are also co-constructed together with all the other entities. The assemblage of heroic action is constructed together with *Ekstra Bladet* as a newspaper that articulates science as a power game rather than a system for producing true knowledge. Furthermore, it would be missing the point to understand these editorial choices as 'merely' a question about media sensationalism. What *Ekstra Bladet* and the assemblage of heroic action produce can be seen as a fundamental cultural critique and a speech position that challenges the discourse of scientific evidence (based on systematic, unbiased collection of empirical data). How this possible 'counter power' should be assessed in a broader context, however, is beyond the scope of this paper, and it is therefore an open question whether it systematically broadens the field of political contestation of science or whether it is more seen as ironic commentary. On a very different level it should be acknowledged, however, that the different assemblages also are productive in shaping public knowledge about what it means to be a patient and a participant in medical research. In this regard it is interesting to note that a profound scepticism of the core claim of science (i.e. that systematic production of evidence will lead to effective future solutions) is not necessarily connected to low expectations towards specific tangible research projects.

Based on these observations it is crucial that the assemblages should not be interpreted as simple extensions of 'social interest'. Although each of them seems to privilege specific ac-

tors this is not simply a description of a preferred view of society by politicians, scientists and patients, respectively. Instead, the three assemblages offer three different ways of constituting the relations that bring together politicians, scientists, patients, expectations and disease into a coherent collective. As such, they have profound consequences for the governance of science in society. In the assemblage of consumption science is granted resources in exchange of consumption goods under strict external regulation. In the assemblage of comportment, science is granted the highest possible amount of freedom, including economic independence, since this will lead to an uncontaminated production of true knowledge to the long-term benefit of society. The contrast between these two assemblages reflects major controversies about the societal role of science, and suggests that Danish society finds itself with a combination of governance models. One model stresses self-regulation and professional discipline within the scientific community (assemblage of comportment), whereas the other prescribes external regulation and effective control mechanisms enforced by political authority. It is not surprising that the different structures of funding, expectations and responsibilities in these models will clash when they are explicitly confronted as in the present case of gene therapy.

The crucial point is that the different enunciations are not just a question of science communication and public understanding of science. Constructing assemblages in the media shapes the conditions for science governance, because it shapes radically different identities for publics, scientists and politicians. The assemblages have ontological effects, because they construct Danes as different kinds of publics for policy making, as well as different roles for science and different objectives for policy making. It also includes different non-human actors and distribute privileges unevenly. Whereas the assemblage of consumption include consumer rights, public regulation, control systems, contracts and a robust medical science which deliv-

ers effective solutions, the assemblage of comportment includes a logic of scientific enquiry, professional judgement, protocols, moral obligations and science as a fragile system. And it is even more crucial that central elements of the assemblage of heroic action are chance, individual action and power games rather than the very thing, which is at the centre of the other assemblages - science itself. In this way the existence of this assemblage can be seen to contradict current efforts to promote a scientific culture in order to sustain a 'knowledge society', an 'innovation agenda' or even a 'reflexive modernity'. To be a scientific citizen is to acknowledge a relation between the citizen and science, but it is an open question whether the assemblage of heroic action includes the entity of science in a way that makes this relation meaningful.

An essential conclusion of the paper is, therefore, that the identification of the three assemblages points to important questions for the concept of scientific citizenship. By their radically different expectations towards science and their different enunciations of the scientific citizen, the assemblages analysed in this paper construct different systems of governance, and offer different prioritisations of various human and non-human actors.

Notes

¹ The particular analysis presented in this paper has been conducted within the framework of a larger study of the articulation of biotechnology in four Danish national newspapers within a 4½ year period from August 1997, which has included quantitative as well as qualitative content analysis (Horst 2003).

² In this sense the paper can be seen to follow a Foucauldian analytical ambition when it seeks to explore the co-construction of scientific futures and identities as scientific citizens as well as other subject positions in a specific assemblage (Foucault 1992).

³ Controlled readership figures in year 2000 according to the Danish Newspaper Publisher's Association are: *Jyllandsposten* 750,000; *Politiken* 528,000 and *Ekstra Bladet* 515,000 in a population of 5 mill. Danes (Danske Dagblades Forening 2006)

⁴ It should be noted that in the original data collection a fourth newspaper was included, namely the intellectual niche paper *Information*. But since this paper almost totally ignored the story with only 6 small insignificant notes, it has been left out of the analysis.

⁵ A single note on language is necessary. I have translated all the relevant quotes in order to be as loyal to the meaning of the sentences as possible, but I have encountered a problem with the Danish word 'forsoeg', which is used about both medical experiment and medical trial. From the mediated articulations it is not possible to distinguish between these two kinds of 'forsoeg'. In the following, I will primarily use the term 'experiment', since I find it the most suitable terminology in this context. In a medical sense, however, it is probably most correct to sort the activities of Lindkaer Jensen under the headings 'clinical experiment' and 'experimental treatment', but it will become clear that these definitions themselves, and especially the lack of distinctions, are crucial to our understanding of the way these experiments are articulated.

⁶ *Jyllandsposten* 10 July 1999: "Tightened regulations

⁷ *Jyllandsposten* 31 October 1999: "CD proposes increased inspection of gene therapy".

⁸ *Ekstra Bladet* 15 October 1999: "Reprimand to doctors in the gene case from Aarhus".

⁹ *Politiken* 28 July 1999: "Reprimand in cancer research case".

¹⁰ *Jyllandsposten* 22 August 1999: "Patients given good odds".

¹¹ *Jyllandsposten* 25 July 1999: "Doctors criticise Aarhus-politician

¹² *Jyllandsposten* 25 July 1999: "Doctors under severe pressure from patients"

¹³ *Jyllandsposten* 25 July 1999: "In search for genius"

¹⁴ *Jyllandsposten* 25 July 1999: "Doctors under severe pressure from patients"

¹⁵ *Politiken* 29 August 1999: "Beware of panic decisions"

¹⁶ *Jyllandsposten* 22 August 1999: "The price of hope"

¹⁷ *Ekstra Bladet* 19 September 1999: "Liver cancer patient cured with genes"

¹⁸ *Ekstra Bladet* 7 September 1999: "The system requires book-keepers"

¹⁹ *Jyllandsposten* 11 July 1999: "Professor speaks out"

²⁰ *Ekstra Bladet* 15 October 1999: "Reprimand to doctors in the gene case from Aarhus".

²¹ Compared to other studies of scientific citizenship, however, it is interesting to note that it is not organised patient groups, but the patient as an individual consumer or object of science which is in focus.

References

- Andersen, I-E. and B. Jaeger. 1999. Scenario workshops and consensus conferences: towards more democratic decision-making. In *Science and Public Policy* 26 (5): 331-40.
- Bauer, M. 2002. Arenas, Platforms, and the Biotechnology Movement. In *Science Communication* 24 (2): 144-161.
- Berkowitz, D. ed. 1997. *Social meanings of news*. Sage Publications.
- Brown, N., B. Rappert, and A. Webster. 2000. Introducing contested futures: from Looking into the future to looking at the future. In *Contested Futures: A sociology of prospective techno-science*, edited by N. Brown, B. Rappert, and A. Webster, 3-20. Aldershot: Ashgate.
- Cook, T. E. 1998. *Governing with the news*. Chicago: The University of Chicago Press.
- Dean, M. 1999. *Governmentality - power and rule in Modern Society*. London: SAGE Publications Ltd.
- Danske Dagblades Forening. 2006. *Læsertal 2000-2004*. Available from <http://www.danskedagblade.dk/dCMS/application.do>. Downloaded October 2006.
- Durant, J. 1999. Participatory technology assessment and the democratic model of the public understanding of science. In *Science and Public Policy* 26 (5): 313-319.
- Foucault, M. 1992. *The archaeology of knowledge*. London: Routledge.
- Foucault, M. 2000. Governmentality. In *Michel Foucault: Power*, edited J. D. Faubion, 201-222. London: Penguin.
- Gutteling, J. M., A. Olofsson, M. Kohring, B. Fjæstad, A. Goerke, M. Bauer, and T. Rusanen. 2002. Media coverage 1973-1996: trends and dynamics. In *Biotechnology. The Making of a Global Controversy*, edited by M. Bauer and G. Gaskell, 95-128. Cambridge: Cambridge University Press.

- Habermas, J. 1991. *The structural transformation of the public sphere - an inquiry into a category of bourgeois society*. Cambridge: The MIT Press.
- Hedgecoe, A. and P. Martin. 2003. The drugs don't work: Expectations and the shaping of pharmacogenetics. In *Social Studies of Science*, 33 (3): 327-364.
- Holtzman, N. A. and T. M. Marteau. 2000. Will genetics revolutionize medicine. In *The New England Journal of Medicine*, 343 (2): 141-144.
- Horst, M. 2003. *Controversy and Collectivity: Articulations of Social and Natural Order in Mass Mediated Representations of Biotechnology*. PhD. Thesis, Doctoral School on Knowledge and Management, Copenhagen Business School.
- Irwin, A. 2001. Constructing the scientific citizen: science and democracy in the biosciences. In *Public Understanding of Science*, 2001 (10): 1-18.
- Irwin, A. and M. Michael. 2003. *Science, social theory and public knowledge*. Maidenhead: Open University Press.
- Irwin, A. and B. Wynne. editors. 1996. *Misunderstanding Science?* Cambridge: Press Syndicate of the University of Cambridge.
- Jelsøe, E., J. Lassen, A. T. Mortensen, H. Frederiksen, and M. W. Kamara. 1998. Denmark. In *Biotechnology in the public sphere*, edited by J. Durant, G. Gaskell and M. Bauer, 29-42. London: Science Museum.
- Levidow, L. and C. Marris. 2001. Science and governance in Europe: lessons from the case of agricultural biotechnology. In *Science and Public Policy*, 28 (5): 345-360.
- Locke, S. 1999. Golem science and the public understanding of science: from deficit to dilemma. In *Public Understanding of Science*, 1999 (8): 75-92.
- Locke, S. 2002. The Public Understanding of Science - A Rhetorical Invention. In *Science, Technology, & Human Values*, 27 (1): 87-111.

- McCombs, M. 2004. *Setting the Agenda - the mass media and public opinion*. Cambridge: Polity Press.
- Michael, M. 1998. Between citizen and consumer: multiplying the meanings of the "public understandings of science". In *Public Understanding of Science*, 1998 (7): 313-327.
- Michael, M. 2000. Futures of the present: From performativity to prehension. In *Contested Futures: A sociology of prospective techno-science*, ed. N. Brown, B. Rappert, and A. Webster, 21-39. Aldershot: Ashgate.
- Michael, M. 2001. Technoscientific bespoking: animals, publics and the new genetics. In *New Genetics and Society*, 20 (3): 205-224.
- Michael, M. 2002. Comprehension, Apprehension, Prehension: Heterogeneity and the Public Understanding of Science. In *Science, Technology, & Human Values*, 27 (3): 357-378.
- Miller, S. 2001. Public understanding of science at the crossroads. In *Public Understanding of Science*, 2001 (10): 115-120.
- Nelkin, D. 1979. ed. *Controversy: Politics of technical decisions*. Beverly Hills: Sage Publications.
- Nelkin, D. 1995. *Selling science - How the press covers science and technology*. New York: W. H. Freeman and Company.
- Nelkin, D. and S. M. Lindee. 1995. *The DNA Mystique: The Gene as a Cultural Icon*. New York: W.H. Freeman and Company.
- Priest, S. H. 2001. *A Grain of Truth. The Media, the Public, and Biotechnology*. Lanham: Rowman and Littlefield publishers.
- Rose, N. 1999. *Powers of freedom*. Cambridge: Cambridge University Press.
- Stockdale, A. 1999. Waiting for the cure: mapping the social relations of human gene therapy research. In *Sociology of Health and Illness*, 21 (5): 579-596.

Wynne, B. 1995. Public Understanding of Science. In *Handbook of Science and Technology Studies*, edited by S. Jasanoff, G. E. Markle, J. C. Petersen, and T. J. Pinch, 361-388. Thousand Oaks: SAGE Publications.

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